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Title- Living on: an exploration of healthful cancer survivorship among Grey Nomads

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Abstract

Aim : To explore the experiences of grey nomads living with a diagnosis of cancer.

Background: Cancer is primarily a both a life limiting and a chronic condition of ageing and older people. Older people however are not a homogeneous group, there are several generations and many different groups to be considered. Grey nomads are one such group and are characterised as being retired and travelling domestically for extended periods of time, usually in a caravan or motorhome.

Design: Prospective qualitative phase of a larger sequential explanatory mixed methods project.

Methods: A series of 14 semi-structured in-depth interviews were conducted over 6 months in 2016 with 14 self identified Grey Nomads living with a diagnosis of cancer. Interviews were analysed using thematic analysis.

Results/Findings: Participants travelled despite of, and because of, their cancer diagnosis. These two key themes with their associated sub themes, explain how older people incorporated their cancer related work i.e. managing their cancer related follow-up and treatment health needs into their travelling life; how they normalised it ; and how they developed strategies for healthful survivorship.

Conclusion: Participants were living healthfully in that they were living a lifestyle that promoted their well-being. Participants developed strategies in response to their changed environment and thus created new capacity to support what they wanted to

do. Despite being cancer survivors – some of whom were undergoing active treatment
- participants gained ‘healthfulness’ through their chosen nomadic lifestyle.

Introduction

An increasing number of older Australians, colloquially known as ‘grey nomads’, take to the road on retirement. In 2011 Australia's grey nomad population was estimated to be about 2 per cent of the total population (or about 450,000 people)¹. The seasonal, nature of the grey nomad lifestyle provides challenges for both receiving and delivering health care to support cancer survivorship ². There is a dearth of literature focusing on the health and health needs, cancer related or otherwise, of grey nomads ^{3, 4}.

Background

Cancer diagnoses in Australia increased almost twofold between 1991 and 2012 ⁵. This is a trend that is largely explained by both an increasing and an aging population. Concurrent with the rising incidence of cancer diagnosis is a decreasing associated mortality. This is largely due to improved cancer screening, early diagnosis together with improved and targeted treatments. Five year survival overall has improved from 47% in 1982-7 to 66% in 2006-10 ⁵. As well as being a malignant disease, cancer is a personal experience that affects individuals in far-reaching ways.

For people living on after their diagnosis, cancer is an intimate and integral part of everyday experience, so it is a social and personal issue in addition to a medical

problem. Cancer survivorship has been characterised as living on after a cancer diagnosis ^{6, 7}, and as a life-changing experience ⁸⁻¹⁵, with both positive and negative aspects ⁶. There is little consensus in the survivorship literature, however, as to who is a cancer survivor and when they become one ^{6, 11, 12, 14, 16-18}. For the purposes of this paper, cancer survivors are defined as those people who self-reported a cancer diagnosis in the online survey that formed the first phase of this project.

Frank ¹⁹ suggests that a survivor is someone who has overcome an adversarial event, and that the process of survivorship is a 'craft activity' (p 251). This, he characterises as an embodied skill of surviving. Whilst the science of survival seeks to understand the disease, the craft of survival seeks to understand the human experience of the disease ^{20 pp1475} or as Stephens ²¹ puts it 'living on'. Therefore, this study may be characterised as a study of one activity in the craft of cancer survivorship. As with survivorship, health too is 'grounded in the experiences and concerns of everyday life ... [and it] provides a means for personal and social evaluation' ^{22 pp62}.

Health has been conceptualised as being experienced when an individual has the capacity to support their goals, projects and aspirations ²³ and as being functional ²⁴. McWilliam, Stewart ²⁵ pp7 illustrated this empirically in his study of older people and their ideas about health. Health, they said, is 'being able to do what you want to do' (p7) as well as feeling in harmony with the environment, thus being able to carry out everyday activities within one's own environment. Healthful living is a term that has been used in the literature since 1915 to describe a way of living that is conducive to good health. Further, healthfulness ²⁶ - a concept that has been used variously over several centuries to describe conditions for health and wellness among populations

and more specifically with regard to nutrition - has been developed more recently by Seedhouse Seedhouse ^{27, 28} in his conceptualisation of the foundations theory of health to describe the conditions required for health. Seedhouse argues that autonomy is a central component of health and further suggests that respecting autonomy is more important than creating autonomy ²⁷. If health is the foundation for achievement ²⁸, healthfulness creates the conditions for achievement and thus health.

Given the numbers and the potential vulnerability, older cancer survivors have become an especially important group to study. However, older people are not a homogeneous group. There are several generations and many different groups to be considered; for example grey nomads specifically with their chosen lifestyle. Literature that has explored grey nomadism has largely focussed on the economic impacts of grey nomad tourism ^{4, 29, 30} and the impact of their seasonal travel on existing health services ⁴. There are no reports specifically looking at grey nomads living on with a cancer diagnosis. Therefore, we need to understand more about their experiences and health needs to help generate a research agenda with this group of older people.

The Study

Aim

To explore the experiences, health needs and strategies of grey nomads living on after a cancer diagnosis.

Method

Study design and participant recruitment

This paper reports on the qualitative component of a larger sequential explanatory mixed methods project exploring the health, health needs and experience of grey nomads. Specifically, this component explored the experiences of grey nomads living with a cancer diagnosis. The first phase comprised an online survey of individuals who had travelled around Australia for more than 3 months, during the previous 12 months. Survey data has been reported elsewhere (Author's own). Survey respondents provided their consent and contact details if they were willing to participate in the subsequent interviews. Of those who consented for an interview, individuals were purposively selected if they had reported a cancer diagnosis. Participant recruitment continued until data saturation was achieved, in other words, when emergent themes became recurrent and no new themes or patterns were uncovered ³¹.

All interviews were undertaken by telephone, due to the geographical location of participants, by one researcher during April/May 2016. Semi-structured interview questions focused on health needs, planning, wellbeing and experience while travelling, specifically focused in relation to their cancer diagnosis. In addition, prompts were used to encourage participants to explore their experiences in more

depth. Interviews were audio-recorded and transcribed verbatim by a professional transcription company. Inductive thematic analysis was used to analyse the data, using the Braun and Clarke ³² framework. Firstly, ideas and pre-understandings of the research team were noted prior to data collection consistent with a reflexive approach, which enhanced the trustworthiness and transparency of the research. Then, a second researcher familiarised themselves with the data; generated initial codes; searched for themes; reviewed, named and defined themes; and crafted the report ³². Validity, or trustworthiness, pertains to the credibility, believability and faithful interpretation of participants' experiences ³³. In this study trustworthiness was established through the purposive selection of participants and qualitative approach used to explore the experiences of grey nomads living with a cancer diagnosis. Recordings were repeatedly listened to by the researcher undertaking the data analysis and the verbatim transcripts themed using NVIVO software to manage coding.

Ethical Considerations

Approval for this study was gained from the Human Research Ethics Committees of the University of #### (Ethics Approval Number: HE15/366). Written consent was collected from each participant prior to the interviews. Pseudonyms have been used to preserve confidentiality.

Findings

Of the 316 respondents included to the online survey, 18 individuals identified as having a cancer diagnosis and consented to be contacted for an interview. Data saturation was achieved after 14 in-depth interviews. The duration of most recent travel for these participants ranged from 4 months to 15 years. Interviews lasted between 28 - 42 minutes.

Participants talked about travelling – where they defined travel as being on the road or living in a caravan/motorhome away from home - in two key ways; despite of; and because of, their cancer diagnosis. These two key themes which were further categorised into sub-themes sub themes, explain how older people incorporated their cancer related work - the activities that they undertook to manage cancer treatment and follow-up - and the challenges into their ongoing travelling life and how they developed strategies for healthful survivorship.

Travelling despite a cancer diagnosis

Cancer was not a barrier to travel for the majority of participants because they integrated organising their treatment, follow-up and management of treatment sequelae into their everyday lives. Participants described how they undertook organisational/planning tasks to maintain their continuity of care and described their specific strategies for effective planning. The two key areas that required planning expertise were; organising and managing cancer treatment on the road; and organising follow-up or other health screening. Both of these demands required participants to seek out supplies and services, adapt route planning and email or telephone ahead for appointments.

It's just about planning things and just being aware of whatever If you stopped in a town for a little while and you knew you were going to be remote for a while, you just make sure you go to the doctor and get a new script and get a couple of repeats or whatever on the pills or whatever and then you've got them when you need them (Eric)

I just do a search on the internet to find out who's the nearest town, where is one [GP] and then ring up and make an appointment (George)

Planning expertise

Participants planned travel routes that took into account weather, social commitments and health needs, as well as places of interest. They explained how they specifically developed strategies for planning and organising their routes according to need. Most participants reported taking trips for at least 6-12 months duration for several years at a time. Jack struggled with the heat and thermo-regulation following treatment and had a strategy for this;

We looked online and I said, where's the coolest town in Australia right now [during a particularly hot summer] and it was Esperance. So we said, right let's go there. So we did. That was about 1500 kilometres to Esperance and we went (Jack)

We tried to be back in Brisbane around Christmas every year when we were in the area to have any tests done that we needed to have done
(Norma)

Many participants described how they organised medication and cancer and health treatment histories as documents to carry with them.

I got on the net and researched the local GPs and picked the one I wanted and made an appointment - had an initial long appointment so she got my history - I always travel with a patient summary from my GP in Adelaide
(Freda)

Managing cancer treatment on the road; It's not a big impact

Some participants were managing ongoing treatment such as oral chemotherapy, whilst travelling and had incorporated this into their daily life on the road.

The surgery removes the damaged organ, the ongoing treatment maintains a vigilance and my ongoing medication [oral chemotherapy] keeps me on a level playing field (Clara)... I know I need to have the medication and I put in place strategies to deal with that...

Maintaining treatment regimens required organisation and planning; to get the medications prescribed; and to acquire and store them;

Thalidomide, being a controlled drug obviously, you had to organise from the hospital to send that through to you by post (Betina)

... My GP's very good and of course, you've got 12 months to use them up I think. So I make sure I've got a full box when I travel - when I start out - and a prescription to top up when I go along the way (Clara)

Well my medication has to be refrigerated, so that had to be taken into consideration - that we had refrigeration or some way of keeping it cool - and those sorts of things. But it was not that big an impact (Andrea)

Cancer follow-up; just another component of the travel plans

Cancer treatment frequently requires follow-up for various durations depending on the cancer, treatment and response. The follow-up requirements for attendance and tests had the potential to restrict the nomadic lifestyle of participants but, as experts in their nomadic lifestyle they integrated the demands of follow-up into their everyday life;

It's not difficult. There's nothing to manage. You've got - as I said, the only thing I've got to worry about is getting the - now the four monthly blood test - so my next blood test's not due for another three months now (Betina)

and where necessary, developed strategies to manage follow-up;

I have small doses of irradiated iodine every year up until now and a full body scan and then that's being stretched out now because my levels are marking quite well. So it's ongoing checks to see if the cancer returns (Clara)

I have prostate cancer which was treated and I ... have checks every six months on my PSA levels (George)

The strategies frequently demonstrated an acceptance on the part of the treating team that the participant was an expert in their own survivorship and a relationship with them that acknowledged and facilitated this. The collaborative way of working was the norm;

We just make appointments over the phone and then when they tell us we've got to be back in the Cairns area, we just make sure we're in a capital city and get a flight up. That's all (Debbie)

I checked with my specialist before I left Adelaide and his comment was, when your mammogram's due, have one wherever you are and if the results are not good, give me a call (Freda)

He told me to watch out for pins and needles in your feet and your hands. So once that started happening, I just emailed him and said, oh you said not to

take the drug any more. So that was it. He said, yes. We'll talk about it when I see you next and that was it (Bettina)

Travelling because of a cancer diagnosis

For some participants the diagnosis of cancer had been the catalyst for travel. The priority for participants became to follow their dreams despite any potential risks of travelling independently or boundaries posed by cancer treatment and its sequelae;

I still had a massive big scar across my throat and yes, I said, I'm going. I need to get out there and I need to do things suppose in some ways it made me think I don't have long to live, so therefore let's live life (Andrea)

I just think, well do as much as you can while you can. So that's why we're doing this one (Bettina)

My diagnosis was - in a way it was a blessing that it happened because it was a wake-up call - made me change a lot of aspects of my life and made me realise that life is precious and that we should seize every opportunity to do the things that we want (Norma)

Travelling healthfully

Participants described how their decision to travel and nomadic lifestyle contributed to their healthful survivorship;

We actually felt that our health all improved while we were travelling. I mean we were probably similarly active, but we felt that our health significantly improved while we were travelling - both physically and emotionally (Martha)

Going out and living life to the fullest, is going to make you a happier person, which is going to make your immune system stronger, which is going to make you more able to fight any further cancers (Norma)

Being proactive in looking after their general health was important and participants explained the importance of this and illustrated their expertise in crafting a healthful way of living. They described strategies, planning and organisation for active health promotion for healthful survival and well being;

Mental health is really important because once you let your mental health slip, then your physical health will be affected as well (Andrea)

You have to look after yourself. You have to make sure that you eat as well as you possibly can, because some places you go to you can't buy fresh fruit and vegetables and things like that. So that's important for good health (Andrea)

We always make sure we've got our flu shots now because we're both 70 this year (Clara)

Discussion

This study has shown that participants engaged with a nomadic lifestyle as part of a healthful response to living on from cancer diagnosis. These findings challenge those of ^{4, 34} who reported evidence of inadequate preparation for travelling including lack of health summaries, inadequate medication supplies and unplanned hospital admissions.

The way that Grey Nomads normalise life and live on after a cancer diagnosis and can successfully navigate their survivorship provides a new contribution to the literature. A cancer diagnosis may not be a barrier to a nomadic lifestyle and, for some, it is the catalyst for it. Cancer survivorship has been described as a life-changing experience because it prompts people to re-prioritise what is important in their lives ^{9, 10, 13, 14, 35, 36} or may include adopting a new sense of purpose in life ^{9-11, 15}. Experiencing a 'new normal' may mean adopting a new lifestyle that is focused on health and wellness ^{8, 37, 38} as is demonstrated by the narratives of some participants in this study. Understanding health behaviours such as those described by participants in this study have been cited as a priority area in survivorship research ¹⁸.

The concept of *living on* ²¹ sought to capture the 'going-on-ness' of participants' lives and the way in which they accommodate the disruptions ³⁹ and chaos created by the changes inherent in being a person diagnosed with a life threatening or chronic condition. Over time, these changes to their body, their identity, their way of life – in other words to their environment - become part of the everyday fabric of their lives.

Many participants explained that the diagnosis of cancer was their catalyst to travel. This is consistent with experiences of grey nomads living with chronic conditions (Authors own 2017). In the discourse on survivorship, *living on* is analogous to the 'new normal'. The 'new normal' frequently refers to a transformation in the individual following a cancer diagnosis that can be experienced in a number of domains. The embodied 'new normal'—the way in which people experience their survivorship—comprises the realisation that returning to the old normal may not be easy or possible. Further, it includes adaptation to this fact.

The way that participants talked about the ordinariness of living with cancer and managing both cancer treatment and follow-up suggested that they have normalised their cancer survivorship as a component of their nomadic lifestyle. They have adapted to a changing environment both with regard to their travel and to their health. Participants became experts in managing their both their health needs and their travel needs. They knew how to do things and how to navigate the health system to manage their treatment and follow-up, whilst on the road. As people living on and after a cancer diagnosis with all of the implications that go with that, they adapted to their environment on the road. These changes to their environment had become part of the everyday fabric of their lives.

Canguilhem ⁴⁰ argued that 'health' was essentially the ability of the person to accommodate the challenges posed by a new environment by creating new norms. Good health, Canguilhem ⁴⁰ argued, 'means being able to fall sick and recover' (p.199).

The environment changed catastrophically for both participants with cancer and their primary support persons. The functional norms that participants adopted, both as

cancer survivors and as nomads, were different to their previous norms or the norms of others who did not have cancer or who were not living a life as a nomad. Being diagnosed with cancer and becoming long-term travellers demanded new responses from participants to their environment and a new relationship with it. Participants were actively seeking to experience health by travelling.

Participants chose a healthful lifestyle (Seedhouse 1986, 2009) in that they sought autonomy and chose to immerse themselves in the world. Participants talked of strategies but talked little of struggle or difficulties or symptoms of their cancer, or treatment sequelae or of any difficulties related to their health and being on the road. They simply evaluated the situation – the changes to their environment – and responded with planning and strategies. Participants created their own strategies to work in partnership with health professionals (rather than rely on them) to evaluate risk, monitor their bodies and manage their healthful lifestyle. In doing so, they demonstrated expertise in their planning and organisation. In other words they integrated the work of cancer survivorship ⁴¹ with their everyday work of travel. This is in keeping with other literature describing the increasing active role that people living with cancer and other chronic conditions are required to undertake (Kendall & Rogers 2007, Gao & Yuan 2011, Schulman-Green et al. 2012).

Limitations

As convenience sampling was used in recruiting participants to the initial survey phase with the via social media sites and caravanning forums and groups, potential participants without internet access were not able to participate in the survey and thus the interviews. Participants who consented to interview may have been more confident and articulate and thus able to develop partnerships with health care providers which was crucial to participant's self management and ability to travel and manage cancer treatment and follow-up.

Conclusion

A nomadic lifestyle of Grey Nomads with cancer can be a healthful choice and thus health promoting; it is a normalising process as explained by the concept of living on and also supports a broader notion of healthfulness within cancer survivorship. Participants were living healthfully in that they were living a lifestyle that promoted their well-being. The grey nomads participating in this study developed strategies in response to their changed environment and thus created new capacity to support their goals, projects and aspirations and they - with planning and organisation - were able to do what they wanted to do. Despite being cancer survivors and for some participants, having cancer treatment with its attendant adverse effects, participants gained 'health' through their chosen nomadic lifestyle.

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